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ABSTRACT

This digest provides an overview of autism and Autism Spectrum Disorder (ASD). It addresses: (1) the behavior of individuals with autism, such as developmental difficulties in verbal and nonverbal communication, social relatedness, and leisure and play activities; (2) diagnosis and evaluation of autism; and (3) prevalence of autism and the diagnosis of autism in four times as many boys as girls. The digest also discusses approaches to intervention and educational support for students with autism. It reports that interventions derived from an educational and behavioral orientation have been shown to help children and adults affected by autism, primarily by teaching new skills that enable the person to function more successfully in the daily world of home, school, work, and community interactions. The digest states that people with autism respond better with structure and clear guidelines regarding expectations for appropriate and inappropriate behavior and recommends that the environment include systems or materials that can help the person to comprehend and predict the flow and sequence of activities. Family members are urged to participate in all aspects of assessment, curriculum planning, instruction, and monitoring. The digest concludes with a list of relevant web sites, organizations, and newsletters and journals. (CR)

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AUTISM AND AUTISM SPECTRUM DISORDER (ASD)

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Autism and Autism Spectrum Disorder (ASD)

Glen Dunlap and Mary-Kay Bunton-Pierce

Autism is a developmental disability that affects a person's ability to communicate, understand language, play, and interact with others. Autism is a behavioral syndrome, which means that its definition is based on patterns of behaviors that a person exhibits. Autism is not an illness or a disease. It is not contagious and, as far as we know, it is not acquired through contact with the environment. Autism is a neurological disability that is presumed to be present from birth and is always apparent before the age of three. Although autism affects the functioning of the brain, the specific cause of autism is unknown. In fact, it is widely assumed that there are most likely multiple causes, each of which may be manifested in different forms, or subtypes, of autism. Future research will help us understand the etiologies of autism.

Autism Spectrum Disorder (ASD) is an increasingly popular term that refers to a broad definition of autism including the classical form of the disorder as well as closely related disabilities that share many of the core characteristics. ASD includes the following diagnoses and classifications: (1) Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS), which refers to a collection of features that resemble autism but may not be as severe or extensive; (2) Rett's syndrome, which affects girls and is a genetic disorder with hard neurological signs, including seizures, that become more apparent with age; (3) Asperger syndrome, which refers to individuals with autistic characteristics but relatively intact language abilities, and; (4) Childhood Disintegrative Disorder, which refers to children whose development appears normal for the first few years, but then regresses with the loss of speech and other skills until the characteristics of autism are conspicuous. Although the classical form of autism can be readily distinguished from other forms of ASD, the terms autism and ASD are often used interchangeably.

Individuals with autism and ASD vary widely in ability and personality. Individuals can exhibit severe mental retardation or be extremely gifted in their intellectual and academic accomplishments. While many individuals prefer isolation and tend to withdraw from social contact, others show high levels of affection and enjoyment in social situations. Some people with autism appear lethargic and slow to respond, but others are very active and seem to interact constantly with preferred aspects of their environment.

Behavioral Description

Individuals with autism are characterized primarily by developmental difficulties in verbal and nonverbal communication, social relatedness, and leisure and play activities. All individuals with autism experience substantial problems with social interactions. In addition, people with autism often exhibit unusual, repetitive, and perseverative movements (including stereotyped and self-stimulatory behaviors), resistance to changes in routines and in other features of their environments, apparent oversensitivity or undersensitivity to specific kinds of stimulation, and extreme tantrums, aggression or other forms of acting out behavior. It is also observed that individuals with autism have uneven patterns of skill development. Some people display superior abilities in particular areas (such as music, mechanics, and arithmetic calculations), while other areas show significant delay.

Diagnosis and Evaluation

The principal source for diagnosing autism is the *Diagnostic and Statistical Manual* of the American Psychiatric Association, Fourth Edition (DSM-IV,1994). Although children affected by autism are being identified at earlier ages than was the case previously, the diagnosis usually does not occur until sometime between two and three years of age. Diagnosticians are often reluctant to issue a formal diagnosis before the age at which complex language is expected to emerge. However, early intervention services can still be provided on the basis of developmental delay, even without a formal diagnosis of autism.

A diagnosis of autism is often provided by developmental pediatricians, psychologists, child psychiatrists, or neurologists. At the time of (or prior to) diagnosis, a comprehensive evaluation is typically arranged. Such an evaluation usually includes a neurological examination, tests for biochemical abnormalities, and other assessments designed to rule out physical and diagnostic conditions. A battery of developmental and educational evaluations is also conducted to help develop an appropriate early intervention plan. Family involvement is integral to this entire process.

Prevalence

In 1997, the Centers for Disease Control and Prevention (1999) estimated that a broad definition of autism may be present in as many as one person out of every 500. This estimate suggests that there are roughly 500,000 people in the United States who could be described as having autism or autism spectrum disorder.

It is well established that autism occurs in four times as many boys as girls (NICHCY, 1999) and that there are no known racial, social, economic, or cultural distinctions. Although it is possible that there are some genetic linkages with some forms of autism, there are no associations with particular familial or cultural histories or practices. Earlier theories that implicated parents' behavior in the occurrence of autism have been thoroughly discredited.

There have been occasional speculations about clusters of autism in some areas of the country, and it has been suggested that such clusters may be associated with environmental contaminants or regional medical practices. To date, however, there have been no clear data that support these speculations.

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Approaches to Intervention and Educational Support

Since autism was first identified as a syndrome more than 50 years ago, a variety of intervention strategies have been suggested. These interventions and treatments have risen from a range of theoretical positions, but most have not proven to be effective with large numbers of children. This pattern continues today, with a large number of diverse treatment approaches being touted as uniquely effective in resolving patterns of autistic behavior. For the most part, such claims have not been substantiated in controlled research. The message for families, teachers, and other consumers is to be cautious when considering new, grandiose testimonials, and to be very thoughtful and selective when constructing plans for intervention and support.

Even though autism has attracted an array of spurious treatments, a good deal of real progress has occurred, and some very credible approaches have been demonstrated repeatedly to be effective in improving the behaviors and adaptability of people with autism. Interventions that are derived from an educational and behavioral orientation have been shown to help children and adults affected by autism, primarily by teaching new skills that enable the person to function more successfully in the daily world of home, school, work, and community interactions. Years of research and experience have produced some relevant guidelines for providing instruction and intervention for individuals with autism. For example, it is important that interventions be developed on an individualized basis. The label of autism by itself is not prescriptive. It does not indicate *what* intervention should be provided or *how* intervention should be provided.

As a set of general rules, it is widely agreed that people with autism respond better in a context where there is structure and clear guidelines regarding expectations for appropriate and inappropriate behavior. It is also recommended that the environment include systems or materials, such as written or picture schedules, that can help the person to comprehend and predict the flow and sequence of activities. The focus of intervention and instructional efforts should be to develop functional skills that will be of immediate and ongoing value in the context of daily living. This typically includes strategies for enhancing a person's ability to communicate, to understand language, and to get along socially in complex home, school, work, and community settings.

Another important guideline for intervention pertains to family involvement. To the greatest extent possible, family members should be encouraged to participate in all aspects of assessment, curriculum planning, instruction, and monitoring. Parents and other family members very often have the most useful information about an individual's history and learning characteristics, so effective intervention and instruction should take advantage of this vital resource. Furthermore, because families are so essential in the lives of people with autism, family support that helps strengthen the family system is regarded as a vital element in providing effective intervention for people with autism.

References

American Psychiatric Association. (1994).(4th ed.). *Diagnostic and statistical manual of mental disorders*. Washington, DC: Author.

Centers for Disease Control. (1999). *Autism among children*. (On-line). Available: fact sheet at http:www cdc gov/nceh/programs/cddh/dautism htm.

National Information Center for Children and Youth with Disabilities.(1999). *Autism and pervasive developmental disorder*. (Fact Sheet Number 1). Available from NICHCY, PO Box 1492, Washington, DC 20013. 1-800-695-0285. Also available online at http://www.nichcy.org/pubs/factshe/fs1txt.htm.

Readings and Resources on Autism, ERIC Minibibliography No. E13.

Resources

WEB Sites

Autism Center
http://www.patientcenters.com/autism/news/pdd47990601.htm

Autism Resources
http://www.autism-resources.com

OASIS (information about Asperger Syndrome)
http://www.udel.edu/bkirby/asperger/#education

TEACCH Program (Treatment and Education of Autistic and Related Communication Handicapped Children)
University of North Carolina, Chapel Hill
http://www.unc.edu/depts/teacch/

Organizations

Autism Society of America
7910 Woodmont Avenue, Suite 650
Bethesda, MD 20814-3015
(301) 657-0881
http://www.autism-society.org

Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116
(619) 281-7165
http://www.autism.com/ari

Cure Autism Now (CAN)
5225 Wilshire Blvd., Suite 503
Los Angeles, CA 90036
(213) 549-0500
Email: CAN@primenet.com

Newsletters and Journals

Journal of Autism and Developmental Disorders
Plenum Publishing Corp.
227 W. 17th St.
New York, NY 10011

Focus on Autism and Other Developmental Disabilities
PRO-ED
8700 Shoal Creek Blvd.
Austin, TX 78757-6897

Journal of Positive Behavior Interventions
PRO-ED
8700 Shoal Creek Blvd.
Austin, TX 78757-6897

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